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Psycho-ophthalmology, parental stress and blindness: a narrative literature review

Psicoftalmologia, estresse parental e cegueira: uma revisão narrativa de literatura

Psicoftalmología, estrés parental y ceguera: una revisión narrativa de la literatura

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KEYWORDS:
Stress, Psychological; Parenting; Blindness.

ABSTRACT

High parental stress may be reflected in a decrease in the quality of the blind child's care, in addition to increasing parents' health risks. A narrative literature review is necessary to put this issue into historical context and to guide new studies on this topic. This study is a narrative literature review that complies with the SANRA standard and aims to put this subject into narrative and historical context with an ophthalmologic medical background. Parental stress in ophthalmology is a relevant field of study that requires further research, particularly in cases of low visual acuity and blindness.

PALAVRAS-CHAVE:
Estresse Psicológico; Parentalidade; Cegueira.

RESUMO

O estresse parental elevado pode refletir na queda da qualidade do cuidado da criança cega além de elevar o risco de danos à saúde dos pais. Faz-se necessária uma revisão narrativa de literatura para contextualização histórica e para balizar novas pesquisas relacionadas ao tema. Este estudo é uma revisão narrativa de literatura, está em conformidade com o padrão SANRA e objetiva a contextualização narrativa/histórica em seu *background* médico oftalmológico. O estresse parental em oftalmologia é um campo de estudos relevante e que necessita de mais investigações principalmente na baixa visão e na cegueira.

PALABRAS CLAVE:
Estrés Psicológico; Responsabilidad Parental; Ceguera.

RESUMEN

El estrés parental elevado puede reflejarse en la disminución de la calidad del cuidado del niño ciego, además de incrementar el riego de injurias a la salud de los padres. Se hace necesario una revisión narrativa de la literatura para la contextualización histórica y asimismo para señalar nuevas investigaciones relacionadas al tema. Este estudio es una revisión narrativa de la literatura y está en conformidad con el estándar SANRA. Tiene por objetivo la contextualización narrativa/histórica en su escenario médico oftalmológico. El estrés parental en oftalmología en un campo de estudios relevante y que necesita más investigaciones, sobretodo acerca de la baja visión y ceguera.

INTRODUCTION

"It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has" (Sir William Osler)[1].

Ophthalmology is an exciting and constantly evolving medical specialty. Philosopher Søren Kierkegaard (1813–1855) stated that "one has to look at the past to understand life; however, one has

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Received on: Jun 18, 2019. **Accepted on:** Aug 30, 2019.
Funding: No specific financial support was available for this study. **Disclosure of potential conflicts of interest:** None of the authors have any potential conflict of interest to disclose.
How to cite: Souza-Silva J, Barbosa M, Botelho N. Psycho-Ophthalmology, Parental stress and blindness: A narrative literature review. eOftalmo. 2019;5(3):135-42.
DOI: 10.17545/eOftalmo/2019.0022

to look to the future to live"[2]. Therefore, there are moments when standing on the shoulders of giants and looking back reflecting on the contribution and legacy of great professionals from the past helps to put a given theme into its proper historical and evolutionary context. This kind of review also helps one to look further, trying to find gaps in the existing knowledge and foster future research and contributions on that theme. At the very least, it refreshes concepts that help build a better ophthalmological practice.

Some eye diseases, including blindness[3], low vision[4], strabismus[5], eye cancer[6], and retinopathy of prematurity (ROP)[7], may cause significant psychological changes in affected individuals and their families.

This stud's objective was not to make ophthalmologists specialists in psychology or psychiatry but to stimulate discussions in these fields of expertise in the ophthalmological context, highlighting the importance of identifying psychological changes in the patients seen by ophthalmologists. This approach can improve the patients' relationship with their physicians, their confidence, adherence to proposed clinical or surgical treatments, and quality of life. It can also facilitate referral and improve parental, family, and social relationships.

METHODOLOGY

This narrative literature review[8-12] was conducted from January to April 2019. A literature search was performed in the databases PUBMED/MEDLINE, Google Scholar, and gray literature. The keywords used were *psycho-ophthalmology, psychology, stress, parent*, ophthal*, blind*, low vision, child*, glaucom**, and *squint**. This review complied with the quality standards of the Scale for the Quality Assessment of Narrative Review Articles (SANRA)[13] and aimed to answer the following question: "What approaches, methodologies, and results are available in the literature combining the themes of psychology, blindness, and vision?"

NEED FOR A HOLISTIC APPROACH TO THE PATIENT: HISTORICAL CONTEXT

The relationship between mind and body has been a subject of interest throughout history. Socrates stated that "one should not attempt to cure the eyes without the head or cure the head without the body; so, one should not attempt to cure the body without the soul either"[14].

In ancient times, mental illnesses were commonly attributed to supernatural phenomena such as evil spirits, and patients were given treatments that were sometimes brutal, including trepanation, i.e., the perforation of the skull for the escape of evil spirits[15].

Superstition, magic, and healing mingled, the figures of the priest and the physician overlapped, and the act of healing was intimately linked to the supernatural. Ancient civilizations such as the Assyrians and Babylonians (3000 BC) stated that eye diseases were attributed to Pazuzu, the demon of the southwest wind[16].

Hippocrates (460–370 BC) regarded human beings as indivisible units and gave medicine a more scientific and holistic approach. With respect to the holistic approach to treatment, he once stated, "To heal the body, it is necessary to have knowledge about things as a whole." This "whole" includes mental health. His concern about the mental health of patients was so strong that he developed the first nosological classification of mental disorders into melancholy, mania, and paranoia, based on the theory of humors[17].

THE CONCERN WITH PSYCHOLOGICAL CHANGES IN OPHTHALMOLOGY: THE NEED FOR A HOLISTIC APPROACH

Ernst Fuchs, an ophthalmologist and professor at the University of Vienna, wrote an ophthalmology treatise in the 19th century[18] that was used as a reference for decades; his teachings demonstrated extraordinary knowledge, and he was considered an ophthalmologist ahead of his time. He was already concerned about holistic approaches to eye care:

> "In this respect, we must remember that we are treating patients, not their eyes, and therefore we need to consider all physical and mental factors that may affect their view of life and determine the need for refractive or other correction"[19].

The care of the individual as an indivisible being should be the focus of attention of physicians. In this context, the ophthalmologist should pay attention to the psychological conditions of patients because these conditions may affect the natural history of eye diseases, as well as the patients' parental, family, and social relationships.

PSYCHO-OPHTHALMOLOGY: A BRIEF NARRATIVE

William H. Bates is considered the creator of psycho-ophthalmology[20]. In 1920, he wrote in his book *The Cure of Imperfect Sight by Treatment Without Glasses*[21] that eye exercises associated with "positive and pleasant thoughts" could cure refractive errors[20]. In his book *Fads and Fallacies in the Name of Science*, Gardner[22] called Bates' work "a fantastic compendium of wildly exaggerated case records, unwarranted inferences, and anatomical ignorance." However, the question is what would be psycho-ophthalmology's true focus.

Psycho-ophthalmology is the interaction between ophthalmology and psychiatry[23]. It studies psycho-affective disorders in the context of eye diseases. This will be the guiding concept to be considered for selecting and analyzing articles in this narrative literature review.

PSYCHO-OPHTHALMOLOGY IN THE EARLY 20TH CENTURY

The analysis of articles on psycho-ophthalmology published in the early 20th century allows proposing two conditions: 1) Psychological, neurological, or psychiatric disorders that affect vision and 2) Eye diseases that cause emotional problems.

Psychological, neurological, or psychiatric disorders affecting vision

Small[24] performed a review of the literature published from May 1918 to June 1919 and published it in a section of the 1919 *Ophthalmic Year Book* that discussed the anatomy of visual centers and tracts and addressed neurological and neuro-ophthalmic problems. This section also discussed the association between visual and mental disorders. In the early 20th century, there was no robust scientific explanation for some ocular phenomena, and their causes were commonly attributed by exclusion to psychological changes. The studies reviewed by Small[24] contain terms (most of them are now obsolete but are cited here for informational purposes) such as "hysteria," "hysterical blindness," "post-emotional stress blindness," "transient amblyopia due to cerebral concussion following the explosion of bombs," "ophthalmic migraine," "delusions and hallucinations," "hysterical amblyopia," "transient blindness associated with hysterical seizures," and "eye tension." Shastid[25] later defined "hysteropia" as the set of ocular manifestations of hysteria. These symptoms usually resulted from emotional stress associated with extreme events (family losses or wars) or systemic/neurological diseases that affected vision, including optic-chiasm lesions, pituitary tumors, migraine, and epilepsy. The therapies for hysterical disorders included "treatment by suggestion" or "staying in a dark room for three days."

In these examples, the etiology was an external factor that eventually led to visual changes. Harrington[26] proposed a classification for eye disorders of psychogenic origin.

In 1910, Freud[27] reported that some so-called hysterical patients were blind because of a dissociation between conscious and unconscious processes in vision. His hypothesis was that the loss of vision was the result of psycho-affective conditions, rather than their cause.

Role of eye disorders in the causation and evolution of emotional problems

In psycho-ophthalmology, visual impairment appears as a central, relational, originating, or aggravating element of psychological/psychiatric disorders with effects on individuals, relatives, caregivers, and health professionals, in the family, community, and social contexts.

Inman (1921)[28], who was both an ophthalmologist and a psychoanalyst, studied strabismus and found no evidence of mental stress in children with that condition. However, he started to study these patients' families and found that in such cases, either there was a pattern of oppressive parental rigidity or one of the parents was very reserved and inaccessible.

In 1927, Edwards[19] studied the psychological aspects of refraction, contextualizing the multiple psychological changes observed by ophthalmologists in daily practice. He encouraged professionals not to be daunted by these clinical conditions and quoted two texts by Ernest Fuchs that reinforced the holistic nature of the care that ophthalmologists should give, emphasizing physical examination and determining the relationship between eye diseases and mental/behavioral aspects.

In 1929, Inman[29] questioned psychological stress as the cause of acute glaucoma attacks (which was the traditional medical thinking at the time), leaving room for further research to better elucidate the underlying mechanisms.

In 1946, Helen Flanders Dunbar, known as the mother of psychosomatic and holistic medicine,[30] reviewed 2400 articles published between 1910 and 1945 in every medical specialty on the influence of emotions on the human body[31]. Chapter XIII addresses ophthalmology in 15 pages, analyzing the context, objectives, results, and main conclusions/characteristics of the studies that evaluated the intersection between psychosomatic diseases and vision. Dunbar made general considerations on the psychosomatic aspects of ophthalmology, considered the number of articles on the relationship between psychological changes and vision to be small, and presented articles that expressed a possible negligence of ophthalmology in distancing itself from psychology and psychiatry. The author found that the effect of eye diseases on psychological states was more evident than the effect of these states on anatomical or functional changes. Psychological symptoms are an expression of conflicts in the whole personality, and the study concluded that these conflicts were the most relevant factor.

In 1940, Shoenberg[32] showed that the anxiety state in glaucoma was similar to the anxiety experienced under conditions of weather variations, poor lighting, poorly balanced diets, cardiovascular disorders, acute febrile illnesses, and sudden increase in blood pressure, i.e., there was no significant variability in anxiety levels between glaucoma and those other conditions mentioned.

Shoenberg[14] also stated that in addition to the specific treatment of glaucoma, the patient's ego, individual limitations, and psychological problems should be treated as well.

In 1947, Hibbeler[33] assessed whether emotional factors played a prominent role in the treatment of glaucoma. The study group involved 27 patients with glaucoma. The instrument used was the Minnesota Multiphasic Personality Inventory, with a total of 566 closed (true or false) questions, but only the first 366 were used. The author concluded that patients with primary glaucoma had personality disorders more often. To the best of our knowledge, the study was the first to use a specific instrument to evaluate the correlation between psychological disorders and eye diseases.

Hartmann[34] highlighted that the objective of bringing to light the association of psychological and ophthalmological disorders was not to make ophthalmologists become experts in psychology or psychiatry, but rather to remind ophthalmologists that mental health issues should be considered during anamnesis. Psychiatrists and psychologists are the professionals who are adequately trained to evaluate and manage patients with psychological disorders. Nevertheless, basic knowledge of psychology and humanization of care by ophthalmologists allows comprehensive eye care. Furthermore, understanding the patient's feelings and humanizing care can improve surgical outcomes. It is worth highlighting the importance of having a multidisciplinary team because individual treatments complement each other.

The first book on psychosomatic ophthalmology was published by Schlaegel in 1957[35]. Chapter 23 addressed the psychosomatic aspects of blindness. Several topics were covered, including attitudes toward blind people, historical aspects of how society viewed blindness, the role of ophthalmologists in blindness, the patient's reaction to blindness, management of patients with recent blindness, and suggestions of books. I would like to suggest two books myself: 1) *The Adjustment of the Blind*[36], for ophthalmologists, and 2) *Our Blind Children*[37], for parents.

In 1959, Dunbar[38] included a new sub-item to Harrington's classification[39] of ocular manifestations of psychosomatic disorders: eye diseases associated with personality disorders. The author cited the studies by Barry and Marshall[40], Hallenbeck[41], and Elonen[42,43] on the relationship between behavioral disorders and childhood blindness and stated that these authors believed that many, if not all, behavioral problems were not due to blindness but rather due to interpersonal relationships, particularly, the relationship with the mother. The psychopathology that can appear as a reaction to blindness can manifest itself as a prolongation of depressive phases or of masochistic depression with self-reproach and bitterness toward the world[38].

In 1957, Blank[44] showed that congenital blindness did not always impact a child's ego or personality. Nonetheless, this condition was inevitably traumatic in cases in which ego functions were already developed because it impaired the patient's patterns of communication, motility, work (or childhood activities), recreation, and feelings about oneself (body image and other aspects of self-awareness).

Blank[44] believed that pre-existing psychological changes or character disorders made the mother more vulnerable to stress. The author also stated that the parents of blind children were anxious, depressed, and perplexed, unless they received professional help. Mothers felt different, inadequate, isolated, could not relate with mothers of children with normal vision, alternated feelings of pity with recoiling from them,

were reluctant to discuss with friends or relatives the daily problems encountered with the blind child, retracted into themselves, and kept the child away from normal individuals.

PSYCHO-OPHTHALMOLOGY IN BRAZIL

There have been studies conducted in Brazil addressing the association between psychological conditions and visual changes.

In 2002, Mucci[45] evaluated the adherence to clinical treatment of patients with simple chronic glaucoma with and without psychological orientation, and concluded that this orientation increased adherence to treatment and consequently decreased intraocular pressure.

In 2003, Botelho[46] evaluated the psychological aspects of acquired unilateral anophthalmia, the quest for aesthetic recovery with the use of eye prostheses, and the interpersonal relations and social reintegration of patients with anophthalmia. This study also emphasized the importance of multidisciplinary approaches and positive attitudes toward the patient to make coping with the loss easier.

In 2007, Moreira[47] assessed the quality of life and personality styles of patients with keratoconus and concluded that these patients presented psychosocial and quality-of-life changes.

Messa[48,49] studied vision-related quality of life in children with ROP and the psychological effects of childhood eye diseases on parents and caregivers. The Children's Visual Function Questionnaire was used for the quantitative analysis, whereas a psychological interview guided by a previous script and submitted to content analysis was used for the qualitative analysis of 88 participants (43 in the study group and 45 in the control group). The results indicated that there was a statistically significant reduction in the ROP in the intervention group relative to the control group and that ROP impaired vision-related quality of life.

PSYCHO-OPHTHALMOLOGY, PARENTAL STRESS, AND BLINDNESS

Endocrinologist Hans Selye defined the term "stress" in 1936 as a nonspecific bodily response to any demands made on the body[50].

Stress is a popular concept with multiple definitions, but one of them is that it is a phenomenon inherent to human psychological and social dynamics that, on the one hand, involves stimulation or challenges (stressors) and, on the other, results in anguish or tension in the affective domain, together with possible physiological responses such as, increased levels of norepinephrine and cortisol[51,52].

More specifically, parental stress (PS) is the set of processes that lead to adverse psychological and physiological reactions that result from attempts to adapt to regular parenting activities[52].

Excessive PS can lead to dysfunctional parental relationships and to physical and psychological disorders, which in turn may lead to behavioral and emotional problems in children and deterioration of family relationships[53-55]. It is worth noting that the emotional state of parents is fundamental for child development because parents under stress are less responsive to the needs of children.

In addition to the impairment of family relationships and development of childhood diseases, stress can cause physical and psychological disorders and is a significant risk factor to the health of caregivers[51].

The loss of vision impacts all aspects of childhood development, including the physical, social, emotional, cognitive, and educational domains, future employment opportunities, and independence. Therefore, it has a significant social and family impact. Stress levels higher than average can decrease the quality of treatment of blind children[53,55-58].

In 1976, Richard Abidin published the first article about the Parenting Stress Index (PSI), which was under consideration. In 1980, Abidin and Burke[59] published a new model that would later be adopted by the PSI. In 1983, the first version of the PSI was developed in response to the need to assess parental stress in parent–child relationships. This instrument is currently in its fourth version. Data from Selye's studies became one of the four cornerstones of the PSI, and this instrument is the most widely used for evaluating PS.

In 1992, Innocenti[60] was the first to measure PS in parents of visually impaired children using the PSI. Among 725 children with disabilities, PS was measured in 38 parents. The measurement of PS caused by visual impairment was not specifically isolated from PS by other causes, and the respective results were considered inherent to "children with disabilities." The study supported the existence of interventionist attitudes by the families of children with disabilities[60].

A more specific study by Drews[53] (2003) examined 41 preschoolers with congenital cataract to eva-

luate the perception of PS in caregivers. According to this study, to maximize adherence to treatment and visual outcomes, ophthalmologists can consider treatment modalities that minimize PS, monitor PS in parents of children with congenital cataract, and provide psychosocial interventions to reduce stress.

Sakkalou[61] (2017) performed a longitudinal-cohort cross-sectional study to determine PS, anxiety, and depression patterns in mothers of children aged 1 to 2 years with severe visual impairment. This author used the third edition of the PSI Short Form (PSI-SF), comprising 36 items and three subscales. The total sample comprised 90 participants, and the follow-up time was 12 months. Eleven patients were lost to follow-up. The author concluded that mothers of visually impaired children aged 1–2 years were at a higher risk of PS, and that PS increased the risk of anxiety and depression.

COMMENTS

Some visual problems in childhood, such as blindness, congenital glaucoma, strabismus, and eye cancer, can affect the psychological health of children and their parents. The studies analyzed in this narrative literature review indicate the fragility and even the neglect of psychological factors in ophthalmological practice. PS has been studied in the context of ophthalmology only in the past three decades. Furthermore, the few available studies either address specific conditions (congenital cataract) or have limitations related to the age of children (0–2 years) and the site of data collection (hospitals).

CONCLUSION

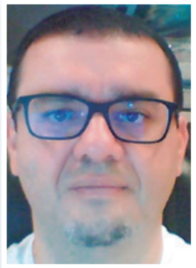
The number of studies on the association of PS and childhood blindness is small. However, this relationship needs to be further evaluated. The analysis of psychodynamic factors in the context of ophthalmology has been historically neglected, but it can improve the doctor-patient relationship, treatment results, parental health, and the care of blind children.

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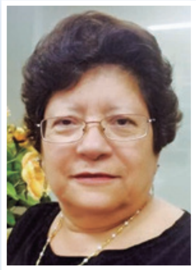
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